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Children Without A Voice

January 2012

Report on children with symptoms of severe depressive
devitalisation who have been refused asylum and protection in
Sweden

Etikkommissionen i Sverige

A Network for Human Rights in the Asylum Process

<http://www.etikkommissionenisverige.se/>

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The report is part of the work of the Etikkommissionen i Sverige (the Ethics Commission in Sweden). Etikkommissionen promotes human rights for people who are seeking asylum in or who are living in Sweden without officially approved identity (undocumented) and who are in need of protection. Etikkommissionen contributes to a humane and generous perception of fellow humans in need of protection and defends the right to asylum. Etikkommissionen works to safeguard the right of asylum and that its preliminary work is maintained under the Aliens Act in accordance with the 1951 Geneva Convention on refugees and other relevant conventions to which Sweden is a signatory. For more information about Etikkommissionen i Sverige see website: <http://www.etikkommissionenisverige.se/>. This inventory and report were conducted and written through voluntary (unpaid) activities. Karin Johansson Blight translated the report into English.

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We would like to thank... the refugee families, in particular, who have with trust and great generosity fully participated to help not only themselves but also other persons. The contact persons /advocates who have contributed with information to the inventory. The Human Rights group (MR Hörnan) within Doctors of the World Sweden/Läkare i Världen and the Asylkommitten working with human rights and provision of psychosocial and judicial support to undocumented migrants. Doctors of the World Sweden/Läkare i Världen for administrative support and volunteers for their work. Madeleine Galloni, Law student, Stockholm University, for her conscientious, thorough and systematic input in the collection of data. Ed Paulette, systems administrator, Uppsala University, for a very welcome contribution to the lay-out of the report and for English language advice. Sten de Geer, Solicitor, for valuable expert advice and for comments regarding the right to asylum and the judicial process. The Swedish Paediatric Society's Working Group for Refugee Children (Svenska Barnläkarföreningens Arbetsgrupp för flyktingbarn) who suggested the inventory for children with symptoms of severe depressive devitalisation who had been rejected permission to stay— especially, it's Chair, Henry Ascher, Associate Professor and paediatrician, for critical scrutiny of the report and important comments on the paediatric parts. Göran Bodegård, specialist in Child and Adolescent Medicine and Psychiatry, and the 'grand old man' of knowledge about children with symptoms of severe depressive devitalisation, for invaluable comments and for the safeguarding of medical ethics. Hans-Peter Søndergaard, specialist in general psychiatry and psychotherapist, for equally important expert advice and comments on potentially traumatising life events. Kjell Asplund, Professor Emeritus, for the knowledge base discussion. Mr Andrew Blight for proof reading the English version.

Preface

The position that the Swedish Government took in the beginning of the 21st Century in relation to asylum seeking children who suffered from severe depressive devitalisation, triggered a development of a politicised ideology of care. In 2004, the Government commissioned the Foreign Ministry (Migration Minister) to investigate the reason behind this illness amongst asylum seeking children. By appointing the Foreign Ministry to the mission, the Government indicated that the children were not ill in a real sense. This was as absurd as if the Ministry of Agriculture had been allocated the responsibility for the Swine Flu epidemic! The children's condition was regarded as a previously unknown phenomenon, which manifested itself as an epidemic amongst asylum seekers in Sweden. The child psychiatric field explained that this is a group reaction amongst families who were living under threat and where there may have been a possibility of a secondary gain (i.e. a residence permit).

Psychological trauma was said not to contribute. It was also claimed that the children fell ill because of rejections on their asylum applications, only to recover once the families were granted residency. The National Board of Health and Welfare disregarded previous knowledge as the cases described in the international literature did not concern asylum seekers or minorities and it was emphasised that it is important "to always consider the possibility that the condition is of a manipulative nature".

An adequate medical investigation was never initiated and the direction of care was supported by an unconfirmed consensus made by 25 clinical head managers within the child psychiatric services, which claimed that there was unequivocal and convincing experience from a large number of cases showing that in-patient care quickly institutionalised and worsened the children's states of depressive devitalisation, and thus, inpatient care within child psychiatry was to be avoided.

In the end (in 2006), albeit that the Government appointed investigator admitted in her conclusion that there was no evidence that the children would have been manipulated by their parents, the condition was said to be due to multiple causes, to be mysterious in nature and a unique Swedish phenomenon. The chapter on the 'apathetic children' was considered concluded, and the theory of a multidetermined cause relieved all actors, at all levels of responsibility!

Moreover, since the children had not been given any diagnoses, they were not recorded in health care registers and hence they "disappeared" when the Government investigation stopped. The leadership of the child and adolescent psychiatric services (BUP) and the National Board of Health and Welfare (SoS) had rendered the children invisible, and by doing so they also

hindered the development of knowledge that could have progressed within an adequate medical line of care.

New cases of children with symptoms of depressive devitalisation and anxiety syndrome, developed during the process of asylum, have since been identified, acknowledged and seen by voluntary care givers outside the Swedish health care system. However, the authority providing the most persistent information about the continued occurrence of the children is the Swedish Migration Board, an authority with no caring role but who, as per its commission, question the genuineness of the condition.

Since 2004, reports and collated knowledge about the children with depressive devitalisation have not been recognised as important by the National Board of Health and Welfare (SoS). What these reports show though is a heavy burden of psychologically traumatising experiences underlying the development of symptoms of severe depressive devitalisation. The gathered knowledge also shows that the relationship between illness incidence and rejections on asylum applications is not causal. Moreover, the majority of children fell ill before the children's situation was highlighted by the media, hence the media focus could not have started any psychiatric contagion. Furthermore, adequate health care had been shown to give a much better impact than the correctional-type behavioural treatment offered by the BUP management; i.e. contrary to the embarrassing position statement made by the SoS, which suggested that results from the Swedish clinical context were anecdotal and unimportant for planning of treatment since a decision already had been made not to treat the children as inpatients.

Medical treatment [in Sweden] has to be built on 'science' and 'proven experience'. BUP's position prevented an adequate scientific assessment of the children's situation. The claimed 'lack of knowledge' was very much embraced by decision makers at various levels and became an excuse for omitting normal care and treatment to these children. Though the increased number of clinical observations added medical biological knowledge, this knowledge was not judged as evidence based. In such situation the 'proven experience' becomes even more important. Nonetheless, so far empirical knowledge has not been valued. Thus, the children were rendered invisible as a unique medical problem.

When there is no scientific knowledge or proven experience to guide action, the law becomes dominant. The prevailing interpretation of the new legal framework for asylum is currently the dominating tool for how to treat this group of people.

However what about medical ethics? Do medical ethics not become more important when science and proven experience is not considered sufficient for the formation of targets and visions? It appears that despite a clear international and Swedish regulatory system, the ethical aspects are treated as mere recommendations. These are not requirements that BUP or the Swedish Migration Board need to follow. It is not possible to prosecute violations of

ethical rules - The National Board of Health and Welfare refer to the medical establishment's ethical authorities. However, [these authorities] The Swedish Society of Medicine and the Swedish Medical Association do not wish to shoulder an investigative or prosecuting role, but only work to raise awareness in general. Hence, the Swedish Migration Boards' medical officers are freed from any binding rules of ethical judgement and action.

The establishment who politicised the 'apathetic children' are responsible for this. However, politicians and authorities decisions are based on expert information; and this information was, from the beginning, incorrect and one sided. Everybody who acted against their professional code of conduct in relation to those seeking help, are responsible for not having prevented the re-traumatisation brought on from not being heard and let alone helped in the desperate life situations that can follow from forced migration due to abuse and threats to life and dignity. The sole overarching guarantee left against political induced medical negligence, maltreatment or abuse of children- historically or current- is the individual care givers loyalty towards the basic principles of medical ethics.

The report '*Children Without A Voice*' is evidence to the fact that, at present, it is the stance chosen by individual members of society that upholds Sweden as a humanitarian country. The report is written by people with realistic experiences and not merely by those approaching this issue from a position of power. The report is of tremendous importance as it adds, widens and confirms the empirical knowledge about how children with severe depressive devitalisation and their families are treated in Sweden.

Stockholm, January 2012
Göran Bodegård

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Summary

Background This report contains information about the living situation for children with severe depressive devitalisation who have, together with their families, been rejected asylum and/or protection. During the summer 2011 informal reports were suggesting an increase in the number of children with severe depressive devitalisation who were rejected residency. Etikkommissionen i Sverige was asked to produce a report of the situation in order to raise awareness amongst politicians. **Method** A questionnaire was distributed through an informal network to advocates of relevant families. Study consent was sought in writing or verbally. Data collection was undertaken between 2011-08-30 and 2011-11-22. In total, 24 questionnaires with attached court decisions and certificates from health and social services were included. Every questionnaire corresponded to one family in which a minimum of one child suffered from depressive devitalisation. For the identification of depressive devitalisation, the needs assessment grading 'MAST' was used. 60 individuals were children under the age of 18, of these 30 children were suffering from depressive devitalisation. The families had applied for asylum between 2004 and 2011, which corresponds with the period in which the law about 'particularly distressing circumstances' had been enforced. **Results** Over half of the families belonged to ethnic minority populations. Twenty five children suffered from extremely severe symptoms of depressive devitalisation (MAST grade 2 and 3) and for all of these children there is documentation available that indicates that a) they are part of families where children have experienced potentially traumatising life events such as: beatings, rape, abduction or threats to life, b) parents have been exposed to potentially traumatising life events such as beatings, rape, imprisonment, torture and/or threats to life. In nearly all the families, there is at least one parent who is suffering from sleeping difficulties, low mood, concentration difficulties and/or anxiety. For one third of the children there is not enough information in the documents to enable an assessment of health status. The justifications for rejections reveal gaps in knowledge, questioning and stereotypical perceptions of the children's symptoms and needs for asylum, protection and care. Impediments to enforcement of a deportation decision is often rejected with the argument that it is not the severity of the illness but whether or not the illness hinders the actual deportation that should be assessed. **Conclusion** It is of concern that several of the children's experiences were not included in the asylum application process, even if it formally states in the decisions that the decision adheres to what is in the best interest of the child. Regarding accessible information, it appears that often such knowledge has come to light at a later stage than first instance, i.e. during appeals and/or through health care contacts. Since the families are not considered to fulfil reasons for asylum or protection this contributes to the assessment that health care in the country of origin is accessible and hence rejection is also made in relation to 'particularly distressing circumstances'. In terms of appeals for impediment to enforcements, only the matter of the actual deportation (transportation) is tried.

Background

Introduction

A child was born together with her siblings in Sweden in a family that were seeking asylum. The girl had a comprehensive and well written medical certificate presenting her and the family's history. It states that the girl developed normally for the first four years of her life; she learned to walk and talk at the right time, and she was playing and had play mates. The family sought asylum because of persecution due to their ethnicity. When the girl was four years of age the family was expelled to the parents' country of origin. Soon after arriving at the village they previously had left, the harassment started again. The family's home was broken into during the night. The father was physically abused on a daily basis and was dragged by a rope attached to a car. The mother was raped in front of the children and the children were physically abused. The report to the police was futile. The family moved to a town, where the father received medical treatment for the wounds that the physical abuse had caused. After this the father travelled with the daughter back to Sweden. The father and daughter spent their journey through Europe locked into a truck. On arrival in Sweden, the girl lived separated from her father while they were submitting their asylum claims for the second time. The mother and the other two siblings were not yet in Sweden but were reunited with the father and daughter at a later stage. By this time the girl was suffering from severe symptoms of apathy.

The case study above describes how a previously healthy child, with no underlying somatic illness, can become very ill, in a state of complete function loss/symptoms of withdrawal, having experienced extreme life events [1]. These symptoms of severe depressive devitalisation are a reaction to stress. It can affect both children and adults, through a process of long-term, high intensity, stress exposure in combination with loss of trust and hope. The long-term and severe stress exposure leads to a situation in which the body's stress system (the sympathetic nervous system) and the body's 'brake pedal' (parasympathetic nervous system) burn out [2]. The symptoms are grave, very varied, and include apathy, passivity with anorexia, life-threatening stupor (depressive devitalisation), and attacks of severe anxiety and refusal [1].

Purpose with the report

The purpose of the report is to present information compiled through an inventory undertaken to understand the situation of children who are suffering

from severe depressive devitalisation and their families, after rejection of their asylum and protection application.

Why do the inventory?

The need to map was due to concerns raised in the summer of 2011 at what appeared to be an increase in the level of rejections on right to stay applications in Sweden for children with symptoms of severe depressive devitalisation. This triggered questions about the way in which rejection decisions were made and on what grounds. In response to this, the Swedish Paediatric Society Working Group for Refugee Children contacted the Etikkommissionen i Sverige with a suggestion to compile information about and clarify the children's situation, and to present this to politicians. The report is one of many concerning children with severe depressive devitalisation in Sweden [see 1, 3, 4, 5, 6 and 7].

The scope of the inventory

Twenty four questionnaires with attached court decision documents and certificates (about 100 medical certificates, psychological and social work reports, extracts from patient notes and letters from schools) were included. Each questionnaire encompasses the information for one family, with a grand total of 106 persons: 46 adults and 60 children, of which half show signs of depressive devitalisation. The families sought asylum in Sweden between 2004 and 2011 and have been within the Swedish migration system during the time of the legal enforcement of the law on 'particularly distressing circumstances' [8].

Are all children with depressive devitalisation included?

The total number of children is, as previously reported [6], not known. Not all children living in Sweden with depressive devitalisation are included in this report. In March 2011, the Swedish Migration Board mentioned 75 children [9]. Children who were granted residence permits prior to the inventory are not included, regardless of whether they still showed signs of depressive devitalisation or not. Nor are the four children (and their families) with symptoms of severe depressive devitalisation who have come to our attention since the end of data collection, and who have received rejections on their appeals against deportation.

Method

Data collection period and methods

The data collection was carried out between 2011-08-30 and 2011-11-22. The questionnaire was distributed using “snowball sampling” through informal networks to persons advocating for the families who had been rejections residency. A large number of families were accessed through contacts with health care: hospitals and clinics.

Questionnaire, cover letter and data analyses

A questionnaire was used to summarise information to meet the aim of the inventory (similar to that of a study of patient files). The questionnaire consists of four pages with purpose-made questions. It was developed during the summer 2011 through multi-disciplinary input (psychosocial, medical, and legal). Its purpose was to map information such as the number of children, the level of symptom severity, types of interventions, decisions and the judicial process as well as access to health care and the number of health certificates and reports. The cover letter states that the family advocates needed to ask the families for their permission to use extracts from court decisions, and to inform the families that these may be published in writing and presented in various fora.

Legal statements, court decisions and certificates (medical certificates, psychological reports, extracts from patient medical notes and school reports etc.) are attached to the questionnaires. The inventory was undertaken by three of the four authors of the present report and a University student (16 of 24 questionnaires). Eight questionnaires have been completed by advocates in contact with the families. After completion, the questionnaire responses were registered in Microsoft Excel by the first author of the present report. Report results are presented through frequencies, quotations and summaries of text, followed by a discussion.

Consent form

The family ombudsmen commonly use agreements with the families giving them permission to speak on the family’s behalf. A consent form was added to this type of agreement, outlining to the parents, the purpose of the inventory, that anonymous extracts might be used and that extracts of texts may be presented in various forums (verbally and in writing).

Variable information

The main source of information regarding the children's conditions derives from qualitative descriptions of the children's symptoms and behaviors, made by health care providers and to some extent by parents (written in the questionnaires and/or stated in certificates or extracts from patient notes) (see Attachment 3). Information told by the children themselves is by and large non-existent.

Demography

Demographic information (age, sex, nationality /ethnicity/language) primarily derives from the initial decisions (by the Swedish Migration Board) or other decisions made by the migration authorities (Courts of Appeal).

Depressive devitalisation: definition according to the MAST grades

The information about depressive devitalisation shown in the frequency tables (for example in table 1) and the text is compiled through various sources (for details see Attachment 3). The MAST grading is a description of symptoms used to assess the child's level of functioning/extent of devitalisation in order to decide on the level and type of health care intervention needed. It has been used in the present report to provide a basis for communication of the results; the MAST grading was developed by the Stockholm County Council and has previously been used in the Swedish Migration Board's report from March 2011 [8]. The MAST grading is not a diagnostic instrument to diagnose illness or disorder. It is developed within Sweden and has to our knowledge not been used in other countries. In brief, the MAST grades 1-3 concerns (for further details see Attachment 2):

Grade 1: This level of severity includes children at risk of developing severe depressive devitalisation, who are showing clear signs of depression but who are not in need of somatic care interventions.

Grade 2: The child is withdrawing in terms of communication and contact, has reduced mobility and appetite.

Grade 3: The child is in a state of complete function loss, which means for example that the child is unresponsive, his or her mobility is extremely limited, and feeding needs to be either provided through a nasogastric tube or through spoon feeding. The child needs help with all daily routines including hygiene, getting dressed and is often unaware of bodily signals (such as hunger or going to the toilet).

For children with severe devitalisation, who are not eating or drinking, nasogastric tube feeding can be vital to life. As is described in the MAST grading, MAST 3 (Attachment 2), nasogastric tube feeding is necessary if the child has

lost the ability to swallow. Nasogastric tube feeding is one out of several needs included in the assessment for grade 3.

Another grading noted in the inventory is the two-grade scale recommended by The National Board of Health and Welfare (SOU grade 1 and 2) [6].

For details regarding the type of information/documentation that has been used to identify the MAST grading categories in the present report, see Attachment 2.

Other clinical assessments

Psychiatric diagnoses (26 diagnoses) are available for a total of nine out of 30 children with depressive devitalisation. In relation to the other children information on diagnoses are missing (see Attachment 3 for description of documented diagnoses).

The Swedish C-GAS scale (the Child Global Activity Scale) has been used to assess the level of functioning for three out of 30 children.

Description of Activities of Daily Living (ADL) is included in the documents. However, it is often only mentioned very briefly and it is not clear if a specific assessment tool has been used. Thus, ADL was excluded from the present report.

Illness deterioration

Information about the deterioration of illness primarily derives from qualitative accounts documented in medical certificates, in particular.

Description of 'potentially traumatising life events'

It is documented in the questionnaire, court decisions and medical certificates that the children and their relatives have been exposed to various forms of violence and abuse. The details of events are however sparsely documented. This report highlights the most common forms of violence identified in the documents.

Legal process

Information about the legal process and judicial case work derives mostly from what is available in the families' files. When new information becomes available (such as decisions on the permission to remain), attempts has been made to include this in the inventory. Reasoning around identity documents, 'Pre-judgement negotiation', precedence and judicial process, derives from the legal decisions written by case workers at the migration authorities.

Results

Background information

Four out of 24 families were granted permanent residency through impediments to enforcement during the time of the inventory. Eight families have during this time received decisions of rejection on their appeals against deportation and are thus living under a direct threat of deportation. Twelve families have not yet applied for impediments to enforcements (one of these families is awaiting an initial decision from the Swedish Migration Board).

The number of family members (children below 18, parent/parents, adult children, other adults such as grandparents) range from two to seven persons (median number is four).

Fourteen of 24 families are families with two parents. The median age for mothers (n= 24) is 37 years of age. The youngest mother is 30 years old and the oldest is 51. The median age for the fathers (n=14) is 36 years of age, with the youngest father being 31 years old and the oldest 54.

Ten parents are single parents to a total of 21 children. Of these, one is a father and all others are mothers.

Sixty children are under the age of 18. Of these, 33 are girls in the age of 1 to 17 (median age: 10 years). Twenty-seven are boys in the age of 0 to 16 (median age: 10 years). Five children are adults, although, two of these were under the age of 18 at the time of arrival in Sweden.

Thirty children have symptoms of depressive devitalisation. In nine families it is only the first born child who shows such signs. In three families the first born is a lone child. In 12 families there are more than one child with symptoms of depressive devitalisation, in four of these families a first born child as well as the second or third child in the family shows symptoms.

Thirteen of 24 families belong to minority groups (in the countries from which they fled): eight families belong to the Romani population and five the Uyghur population (Table 1).

Table 1. The total number of persons and children under 18 years of age in total, and the total number of children with depressive devitalisation according to MAST 1-3, by age, gender and ethnicity.

Variables	Number of families (=24)	Number of family members (=106)	Number of children below 18 yrs. (=60)	Children below 18 yrs. with symptoms of apathy		
				MAST 1 (=4)	MAST 2 (=7)	MAST 3 (=19)
Age						
Average (range)	-	-	9 (0 – 17)	10 (1-16)	13 (9-17)	11 (6-17)
Gender						
Girls	-	-	33	3	4	12
Boys	-	-	27	1	3	7
Ethnicity/ Nationality/ Language						
Romani people	8	41	26	-	6	4
Serbia	5	24	14	-	4	2
Kosovo	3	17	12	-	2	2
<i>Language: Romani, Romani-Arli, Serbian, Albanian-romani</i>	5	25	16	-	2	3
Uyghur people	5	22	12	1	-	4
Kazakhstan	6 ¹	25 ²	14 ³	2 ⁴	-	5 ⁴
<i>Language: Uyghur/Russian</i>	5/5	16/19	12/14	1/1	-	4/5
Other Nationality /Ethnicity	10	40	21	2	1	10
Armenia	4	16	7	-	-	5
Azerbaijan	2	8	6	1	-	2
North Ossetia /Russia	1	4	2		-	1
Kyrgyzstan	1	2	1	-	-	1
Uzbekistan	1	4	1	1	-	-
Turkey	1	6	4	-	1	1

¹ Description of ethnicity is missing for one family.

² Description of ethnicity is missing for three persons.

³ Description of ethnicity is missing for two persons.

⁴ Description of ethnicity is missing for one person.

Symptoms of depressive devitalisation, other clinical assessments and the deterioration of illness

Symptoms of depressive devitalisation

Twenty five children have very severe symptoms of depressive devitalisation (Table 1). Half of the children with severe depressive devitalisation belong to minority groups (Romani people: 10 children and Uyghur people: five). Available documentation states that 14 of 19 children with MAST grade 3 are fed through nasogastric tube.

Other clinical assessments

For nine of 30 children with depressive devitalisation, psychiatric diagnoses are documented. The most common diagnoses indicate severe stress reactions (11 diagnoses: F43.0 - F43.9). The most commonly mentioned diagnose is Post-Traumatic Stress Disorder (PTSD). The second most common are diagnoses of depression (F32.1 - F32.9). Two children have diagnoses for apathy (F45.3). Other diagnoses relate to life experiences and their effects on mental health (Z617, Z634, Z738, and Z914) as well as kidney transplant (Z940) (see Attachment 3 for a description of diagnoses).

Clinical assessments regarding levels of functioning according to the Swedish C-GAS scale (scale: 0-100) show < 5, < 10 and < 25 for three of the 30 children where this information is available.

Deterioration of illness

The vast majority of children have experienced a gradual worsening in their health during the time they had been in Sweden (see example in Box 1).

There are also children who had developed depressive devitalisation prior to arrival to Sweden.

Amongst the first signs noted are that children stop speaking, do not want to attend school and eat gradually less. There is also information that children are whining or screaming prior to reaching a state of complete function loss (see Box 1, Questionnaire 7 and 13).

Available information is not complete but it seems as if the health care accessible for the families during the time they are awaiting initial decisions from the Swedish Migration Board or during the appeal process, has been at primary care level, in particular, the Child and Youth Psychiatric Services (BUP) (12 of 24 families). Five families have received treatment within treatment home facilities.

Box 1 Description of illness deterioration

Questionnaire number	Extracts from descriptions of the children's deterioration of illness. The text is as written in the questionnaires
1	The mother and child did not know the whereabouts of the father. They received information that the father was in custody in Sweden. After this the girl started to feel ill. She worried about returning to the country of origin, was sad about her father and did not want to go to school. After the 3rd negative decision the girl stopped eating. Soon thereafter she was in need of nasogastric tube feeding and since has been in a wheelchair and is described as suffering from complete function loss.
2	The girl's condition started to deteriorate during the summer/autumn of 2010. In the middle of December 2010 she stops eating, a nasogastric tube is needed, and after New Year she closed her eyes. In January 2011 she stopped resisting totally.
3	The girl stopped eating in November 2010 and soon after became totally withdrawn [unable to contact]. Was admitted to hospital and in December 2010 it is reported that the girl is fed through nasogastric tube, is assisted with hygiene and has to be carried to the toilet.
4	The girl is, since the winter/spring 2011, more and more passive and quiet. She stopped eating in April-May 2011 and stopped attending school in June 2011, and since then her health has deteriorated.
7	During 2007 the child was screaming, acting out with sudden pangs of sadness, severe symptoms of apathy have since developed after 2008. In August 2008 S stopped walking and talking and did not want to attend school.
9	Gradual deterioration over a period of a year. For one and a half years; spoon fed, has been helped to and from the toilet, is turned in bed, closed eyes, does not communicate etc.
10	2008: stopped speaking, eating poorly, 4 months (May 2009) after arrival in Sweden, depressive symptoms, poor eye contact, and poor verbal response. 2009-2010 anxious, severe signs of depression, December 2010-May 2011. , nasogastric tube feeding, before this stopped talking, no eye contact December 2010-May 2011
13	Since awareness of rejection 2010 total apathy, has stopped whining. Not yet nasogastric tube but nappies

Potentially traumatising life events amongst the children

In 22 families there are children who have been exposed to potentially traumatising life events, i.e. life events that can trigger Post-Traumatic Stress Disorder (PTSD) and/or depression amongst persons who previously have been healthy and well prior to the events (e.g. abuse, rape, threats to life). For more information see Table 2. One child in the two families where information about potentially traumatising life events is missing is receiving nutritional supplements through a nasogastric tube (MAST 3), and one child has MAST grade 1 and one grade 3. The reported abuse is severe. Many of the children have witnessed their parents and siblings, being beaten, raped, abducted and murdered. On these occasions the children themselves have also often been beaten and threatened. The violence has in most instances been carried out by one or more persons who are not members of the family, often during the night. Table 2 shows the number of families with children with depressive devitalisation (MAST 1-3) where the presence of serious violence against children has been identified in the documents. In 15 of the 22 families where children have been exposed to severe physical abuse, 17 children have MAST grade 2 and 3. In 12 families children have been witness to a family member being severely beaten (parent, siblings); in these families there are 12 children with MAST grade 2 and 3. In two families children have been raped. In four families children have been kidnapped and one child was separated from the mother and siblings. Threats to life or violence are documented in 12 families. In all these families children are suffering from severe depressive devitalisation.

Table 2 Potentially traumatising life events amongst children in families with children below the age of 18 with symptoms of depressive devitalisation

Life events for children in 22 /24 families	The number of families where potentially traumatic life events are documented	Children with depressive devitalisation		
		MAST 1 (= 4)	MAST 2 (= 7)	MAST 3 (=19)
Beatings	15	3	5	12
Witnessed beatings	12	2	5	7
Raids, vandalism or attack on the home	4	0	0	4
Rape	2	0	0	2
Witnessed rape	4	0	1	2
Abduction/Forced separation	5	0	2	3
Threats to life or of violence	12	0	5	7

Note: The table illustrates events that have been documented. This means that there will be information missing about potentially traumatising life events in some families where there are children with symptoms of apathy MAST 1-3. Missing information does not mean that the persons have not experienced the event. It only means that we have not been able to access that information. Moreover, in many families more than one event is documented. Finally, the children may have been through other types of equally important events that have not been included in the table or in this report.

Potentially traumatising life events amongst the children's parents

Information about exposure to potentially traumatising life events amongst parents is documented in 21 families. In three families relevant information is missing, three children in two of these families have MAST grade 3.

Table 3 shows the number of families with children with depressive devitalisation according to MAST grade 1-3 and where information is available where parents have been exposed to severe levels of violence.

In 17 of 21 families it is documented that at least one parent has been exposed to severe beatings. For nine families there is information that at least one parent has been a victim of rape. For six families there is information that at least one parent has been detained/imprisoned in the country that the family has fled. There is information that parents have been exposed to torture in four families. In 12 families at least one parent has been exposed to threats to life or threats of violence.

Raids, vandalism or attacks on the home are reported in table 2.

Table 3: Potentially traumatising life events amongst the parents in families with children under the age of 18 who are suffering from depressive devitalisation

Life events for adults in 21 families	The number of families where the information is documented	Children with depressive devitalisation		
		MAST 1 (= 4)	MAST 2 (= 7)	MAST 3 (=19)
Beatings	17	2	6	12
Rape	9	0	1	7
Detained/imprisonment	6	0	0	5
Torture	4	0	1	3
Threats to life or of violence	12	0	7	8

Note: As in Table 2, missing information does not mean that the persons have not been exposed to events summarised in the table. It only means that we have not had access to the information in the inventory. Parents can also have experienced equally important life events, not documented in the table or in this part of the report.

Single parents

In total, ten single parent families are from Armenia and Azerbaijan, Kazakhstan (Uyghur people and one family where ethnicity is unknown), Serbia (Roma people) and Kyrgyzstan.

All 10 single parents are suffering from sleeping problems, symptoms of depression, suicidal thoughts or have attempted suicide and/or are receiving pharmaceutical treatment for depression and PTSD.

Three of the single parents are living in residential care homes. Two have and three are in need of support, in the household. The 10 single parents have a total of 12 children with MAST grade 2 and 3 (ten with MAST grade 3). One mother is taking care of two children in need of nasogastric tube-feeding.

Five single parents to 13 children are living under threat of deportation one of these is the mother with two children with nasogastric tube-feeding. Four single parents have received permanent residency during the time for the inventory. One single parent is not yet at the last stage of appeal (impediments to enforcement).

The potentially traumatising life events include the same type of events as in families with two parents. In one of the 10 single parent families, information about the child's potentially traumatising life events is missing. In the family with the mother to the two children with nasogastric tube-feeding, information about what the mother has experienced is missing, and the severe abuse she has suffered is not presented.

Poor mental health amongst the children's parents and adult siblings

Table 4 shows that in 20 families there is information that at least one parent is showing signs of poor mental health. Common symptoms are sleeping-problems, concentration difficulties, anxiety and fear.

In 20 families it is stated in health certificates that the parents have a reduced capacity to care for the child/ren due to high levels of psychological pressure.

In three families there is information about severe poor mental health for four out of five adult siblings.

In five families, there is information that at least one parent has suicidal thoughts or has attempted suicide; in all families where a parent has attempted suicide there are children with severe depressive devitalisation.

In 15 families a parent is receiving pharmaceutical treatment. The most common treatment is antidepressants; in five families, parents are prescribed antidepressants.

In three families there is information about physical problems such as diabetes, hyperthyroidism and kidney problems.

Table 4 Poor mental health amongst the parents and adult siblings in families with children under the age of 18 with depressive devitalisation

Type of poor mental health amongst the parents and adult siblings (24 families)	The number of families where the information is documented	Children with depressive devitalisation		
		MAST 1 (= 4)	MAST 2 (= 7)	MAST 3 (=19)
Sleeping problems, worry, low mood	20	4	6	17
Suicidal thoughts or attempts	2/3	1/1	1/0	1/3
Psychiatric treatment for depression/anxiety/PTSD ¹	15	2	2	15
The parents have reduced capacity to care	20	4	6	14
Siblings over 18 years old with poor mental health in the form of e.g. PTSD, depressive devitalisation and/or suicide risk	3	1	1	1

¹PTSD- Post-Traumatic Stress Disorder

Note: missing information does not mean that the persons have not been exposed to events summarised in the table. It only means that we have not had access to the information in the inventory.

Legal process

Basis for decision

In many cases it seems that the children's situation is not taken into account by the migration authorities, despite decisions formally stating that they are made in the best interest of the child. In several cases none of the children in the families are mentioned other than very briefly. Often it is only the father's claim for asylum that has been considered.

Proof of identity

It is stated at an early stage in the decisions made by the Swedish Migration Board whether or not the person seeking asylum or protection can provide acceptable proof of identity. An example of how this is presented in decisions can be seen in Box 2.

Of 24 families, five have provided proof of identity (passport/ID) assessed by the Swedish Migration Board as sufficient to make their identities probable or proven.

Eight families have not submitted identity document that were considered sufficient to make identity probable or proven. Seven families have submitted other types of documents such as driver's licences, birth certificates, educational certificates etc. Of these, five have been judged as insufficient, and for the other two the alternative proof of identity has been assessed as sufficient.

Information about proof of identity was not available in the documents assessed for three families. In cases where identity documents are not considered verified by the Swedish Migration Board, the examination of the cases are most often made clear as described in box 3.

Box 2 Standard wording about proof of identity

"In asylum law a fundamental principle is that the asylum seeker should make their need for protection probable. To enable an assessment of the need for asylum, the applicant must first have made his or her identity, nationality and country of residence, probable"

Swedish Migration Board decision (Questionnaire 25)

Box 3 Standard wording about probability

"Since no identity documents have been submitted, their identities cannot be considered verified. The Swedish Migration Board believes it is probable, given what otherwise has been revealed in the cases, that the family is resident [in the country specified]. The examination of the application shall hence be made in relation to the country [specified]"

Swedish Migration Board decision (Questionnaire 2)

'Pre-judgement negotiation'

Under the Swedish Court of Appeal and Supreme Court investigations there is the possibility to propose negotiation to clarify misunderstandings or ambiguities prior to a decision. Unless there are specific reasons not to do so or if it is unnecessary, negotiation is expected [10].

From available information about cases, in two out of 24 families negotiation was proposed and held. For seven families, negotiation was proposed but not approved. In 11 cases mediation has not been proposed. In four cases it is unclear whether negotiation was proposed or not.

Case precedence

The Court set a precedent in a case regarding a boy with depressive devitalisation in November 2001. The boy was granted a residence permit even though he had reached the age of 18 and thus was judged with the more restrictive requirements applied to adults. Further precedence was set by the Government in relation to a boy with severe depressive devitalisation; Government decision 2005-07-07, UD 2005/26449/MAP (see box 4).

For the 24 families included in the inventory, it is clear that these precedents were not discussed in the case decision. In only one case, was the 2009 case precedence referred to. However, in that case it was used contrary to the precedence; in that it was used to justify a rejection of residency rather than to grant it.

Legal procedure

The process of rejection seems to follow a pattern that means, firstly, that the need for refugee status and/or protection is excluded and secondly, that health status which includes whether or not health care is available in the country of origin or other country is dismissed. It appears that information about potentially traumatising life experiences and abuse that the children suffered often comes to light much later in the asylum process, many times, after the family have received rejection of their asylum application (see case report, box 5).

Box 4 Supreme Court precedent setting decision regarding an 18-year old with severe depressive devitalisation

"The medical assessment in the case must be considered to show that [name] suffer from severely poor mental health and his care needs are likely to persist over a longer period of time. The treatment requires that [name] is in a safe environment. Even if psychiatric care, though with major deficiencies- is available for [name] in his country of origin, it must be taken into account that it is events in the country of origin that have triggered his poor mental health. With respect to this and in a overall assessment of [name's] situation, the Supreme Court finds that there are such particularly distressing circumstances to suggest that he should be granted permanent residency. The decision of expulsion concerning [name] should therefore be repealed"

The Supreme Court care precedence
Case number UM 8435-08 (2009)

The refusal of refugee/protection appears in most cases to derive from reasoning about that the story lacks credibility or alternatively that the possibility for protection has not been exhausted in the country the person fled from. This is based, in several cases, on the fact that the persons have not turned to authorities in the country the persons fled (such as the police). When this had not happened, the migration authorities argue that the persons have not exhausted the possibilities for protection (see examples in case description 2, box 6).

The situation in the home country and the need for refugee status/protection seems in this way to be dismissed at an early stage. This dismissal seems to follow throughout the asylum process and differs in this way from the precedence presented in box 4, which in the holistic assessment takes into account life events in the country of residence, which has contributed to the child's poor mental health.

Case description 1

The case description in Box 5 shows examples of a decision from the Court of appeal. The family belong to an ethnic minority whose children show severe depressive devitalisation and it is also documented that the child shows symptoms of PTSD and panic attacks. The family states that they have been exposed to harassments, humiliation and threats due to their ethnicity and the children have been harassed in school, the girl seriously so.

Box 5. Case description: Rejection in the first instance, appeal and on impediments to enforcement.

"The family has not made probable that they are in need of protection as refugees, or subsidiary protection status or otherwise in need of protection. [The child's] health status is not assessed as particularly distressing in accordance with the Alien's Act. For this reason, she cannot be granted residency on the grounds of her health status. She has received medical treatment in the country of residence to deal with her complaints. No other reasons have been suggested, which would indicate that any other family member have reasons that could be considered particularly distressing. Hence, the family cannot be granted residency due to particularly distressing circumstances. In the decision it has particularly been taken into account that [the children] are children, but that it is found that it cannot be regarded as against their best interest to join their parents on their return to the [country of residence]"

The Court of Appeal decision (Questionnaire 23)

Case description 2

The case description in Box 6 regards a family where the justification for rejection derives from information regarding events that the daughter born 1997, the mother and a younger brother have been exposed to. Both children are described as previously healthy. In school in their country of origin, they were harassed and beaten due to their ethnicity. After the event concerning the girl, reported in Box 6, the mother was raped in the room next door to the children for an hour. From the medical certificates it is clear that the mother is very unwell: she is suffering from PTSD, depression, and has made two suicide attempts. She is prescribed sleeping tablets and psychotropic drugs for worry, anxiety and major depression. The girl and her siblings have diagnoses of poor mental health, and the girl is suffering from severe depressive devitalisation. In total, there are ten official reports (nine medical certificates and one psychological report), which confirm the poor health conditions of the mother and children. The narrative raises real concerns that the girl has been exposed to abuse (possibly rape).

The migration authorities are not questioning the health conditions or the events (Box 6). However, the situation in the country of residence is not considered justified as a country that can be fled for refugee reasons. The girl has not made it probable that the country's authorities do not want to protect her and hence there is not a need for protection as the family can be protected in the country of residence. For the family to be given protection in Sweden they would first have had to report the police to the police and only after that would they have the right to international protection.

Particularly distressing circumstances are rejected as there is no evidence presented to suggest that the child would be damaged in her psychosocial development should she return to the country of origin together with her mother and because the events had not been reported to the police. Impediments to enforcement are rejected since there is no information that any new circumstances have emerged.

Box 6. Case description: Justification for rejection and suspected abuse.

Application for refugee- or reasons for protection was rejected:

The Swedish Migration Board "assess the situation for [the minority group] and the general situation in [the country] do not generally mean eligibility for a residence permit". The daughter is not to be considered a refugee since: "You [the daughter] have through your mother stated that when the police came to your home you were dragged into a room and your mother has never been told what happened in that room." "It was never reported to the police since the police don't act on reports made by the [minority group]". "It was not reported to the police after what potentially happened to you when the police came to your house". "You have not made probable that the [country's] authorities would lack the will or ability to protect you against abuse from government officials or against harassments made by citizens [of the country] because you are [belonging to a minority group]".

Particularly distressing circumstances were rejected:

"The Swedish Migration Board judge after an overall assessment of the children's situation in the country of residence and with respect to the principle of children's right to health and development as well as in relation to what the best interest of the child in general demands, that it should not be considered unsuitable for you to return to the country of residence [the name of the country]." "It has not been shown that you be any damaged in your psychosocial development by returning to the [country of residence] together with your mother." "The Swedish Migration Board do not question the family and in particular the children's conditions". "The events are to be regarded as criminal acts committed by individual police officers. These acts are carried out by individual persons and cannot be seen as separate or sanctioned by authorities in [the country of residence]. "The events are not reported by the police". "A prerequisite for being granted international protection is that domestic legal remedies have been exhausted."

The Court of Appeals (Questionnaire 10)

Appeals against deportation

Common justifications for rejections at the enforcement stage are that there are no needs for protection, that no new reasons have been put forward (see Box 7) and that there has been no significant adjustment to Sweden (for example a brief period in Sweden is mentioned as a reason) and thus this factor does not pose a complication for the rejection. It is apparent in several cases that impediments to enforcement relate to whether or not the medical condition poses an obstacle to the practical execution of the expulsion. In other words, firstly impediments to enforcement should occur in exceptional circumstances, and secondly, it is not the severity of the illness that should be assessed but whether or not the condition poses an obstacle to the actual expulsion i.e. the deportation or transportation (see Box 8a: questionnaire 4, 8 and 13 and 8b: questionnaire 15).

Box 7. Case description: Rejection on impediments to enforcement.

"The certificates show amongst other things that [name] fell into a state of depressive devitalisation in August 2010. A state in which it is only just about possible, to give him a sufficient amount of nutrient drink through spoon feeding. Nothing new with regards to the care in that [name] is still cared for at home by his next of kin. There has been no improvement of his health status. The situation is the same as when the assessment for particularly distressing circumstances was made and tried in accordance with 5 Chapter 6§, and no particularly distressing circumstances were found. There is thus no reason for impediments to enforcement. This decision cannot be appealed."

The Swedish Migration Board (Questionnaire 22)

Reasoning about health and poor health

The decision makers are reasoning about health and poor health in the assessments for impediments to enforcement due to medical reasons or particularly distressing circumstances. In several cases reasons are put forward that are outside the decision makers roles and areas of expertise, this includes risks to poor health and the presence of specific diagnoses. Examples of how such arguments have been used to justify the decisions are given below.

- A) In Box 9 and questionnaire 13 Box 8a it is discussed why the psychosocial development of a child with severe depressive devitalisation would not be harmed if the child returns, together with its family, to the country they have fled.
- B) It is also discussed whether or not PTSD can be established, i.e. diagnosed using objective measures (see questionnaire 9, Box 8a). For example in questionnaire 13(Box 8a) the decision makers write that it is

very possible that the child has developed 'severe depressive devitalisation'. After this the Swedish Migration Board argues that the diagnosis PTSD is however 'less certain and cannot fully be established'.

- C) Box 8b, questionnaire 25, concerns a child with severe depressive devitalisation who has been abducted by unknown men and where the family have been exposed to prosecution and threats. In the justification of rejection the decision makers describe at first that they understand that the boy is in need of health care. After that the severity of the child's reduction of function (i.e. the severity of the devitalisation) is discussed, and the decision makers are stating that the child is not ill enough. The decision makers are rejecting the patient notes written by BUP (children and adolescent psychiatry), arguing that these do not document the boy's condition in a satisfactory way. The decision makers argue that from what is mentioned in the submitted documentation they cannot make an assessment about suicide risk. In addition, the Swedish Migration Board is using the lack of medical certificate to verify the child's condition as a justification for rejection.
- D) In questionnaire 13 (Box 8a) the rejection is justified with that the child's weight increase.

Stereotypical perceptions

The decision makers assessments presented in Box 8a and b contain several examples of stereotypical perceptions and insinuations. Such as:

- A) The poor mental health is an expression of something other than those presented by the family with regards to need for refugee status and protection. One example is questionnaire 8 Box 8a and questionnaire 15 Box 8b, which state that it is dashed expectations, economic and social problems.
- B) That the parents would not be prepared to take responsibility for their children (see example in questionnaire 25, Box 8b).
- C) Similarly, (as in point 3, Box 8, Questionnaire 4) it is mentioned that the child would not be harmed by returning with their parent/parents to the country they have fled (see Box 6 and 8). The decision that the parents should not be permitted to stay appears as definite. The migration authorities question is whether or not the child also should be rejected on the application. The decision makers appear to suggest that the only possibility for the child to remain in Sweden is if the child would be harmed by remaining with its parents. In this way, the full responsibility of the future well-being of the child is put on the parents, with no regards to the parents' narratives and original application for protection.
- D) Health care access for the child in the country the child and family have left is then assessed as if it will definitely be available to the child. The opposite must be proven i.e. the child and family need to prove that health care will not be available in the country (see example in box 8b,

questionnaire 25). The grounds to support this type of rejection are often based on general country information (see Box 8a, questionnaire 13). Reference to country information about whether or not the existence of possible discrimination of ethnic minority groups and health care access is probable considering the families narratives and stated refugee reasons is however often missing.

Box 8a Extracts from official decisions on rejections

Questionnaire number	The text is from the questionnaires. The text in bold has been highlighted by the authors of the report to show the parts that are discussed in the general text.
4	<p>Decision on impediments to enforcement: "The Swedish Migration Board does not find any impediments according to 12 Chapter 18§ the Aliens Act (2005:716) against deportation. Considering certificates and other available information with regards to the girl X's condition 'there is, according to the Swedish Migration Board, no medical impediments of the kind referred to in 12 Chapter 18 first paragraph, point 3, the Alien's Act that suggests that enforcement cannot practically be carried out'.</p>
8	<p>The Swedish Migration Board is initiating the test of 12:18 on submitted medical certificates, however then rejects it. In the decisions the government has made clear that it is not the severity of the illness that should be assessed but whether the condition of concern constitutes an impediment to enforcement in the individual case, and there is very little manoeuvre to consider factors such as dashed expectations, worry about return, or for economic or social problems in relation to the case of enforcement.</p>
9	<p>1) Rule of law 12 Chapter 18 § 3. Bill 2004/05 170, page 299 and 266 the Aliens Act, 1 Chapter 10§ 2) the medical officers report 'the diagnosis for depressive devitalisation is describing a typical progression of illness however clear objective measures are largely missing, which makes the diagnosis more uncertain'.</p>
13	<p>Firstly, it is noted that the scope for granting residency for medical reasons at the enforcement stage is very limited. Then it is stated that the father and the best interest of the child should be taken into account and that there are less strict criteria for children. The Swedish Migration Board finds that the medical certificates do not state that there are medical impediments to enforcement and that the question is whether there is another particular reason that enforcement should not be undertaken. The Swedish Migration Board argues that the medical certificates shows that it is very likely that the girl has developed depressive devitalisation of a serious nature but that the diagnosis PTSD is less certain and cannot be clearly established. Neither is she suffering from a somatic illness, and she has even increased in weight. It is clear that the girl is not cared for in hospital but at home and that other than nasogastric tube feeding she is not on any other form of medication/treatment. The dad must be considered to have the capacity to care. The medical certificates have no information about planned care in Sweden. It is not clear that medical treatment in Sweden is a must for the girl to recover, and it is not clear that a return to [the country that the family has fled from] would harm her psychosocial development. The country information shows that there is access to nutrition in [the country the family have fled] as well as diverse medical specialist competence. There is no reason to terminate the enforcement.</p>

Box 8b Extracts from official decisions on rejections, continuation from box 8a

Questionnaire number	The text is from the questionnaires. The text in bold has been highlighted by the authors of the report to show the parts that are discussed in the general text.
15	<p>'Of Bill 2004/2005 170 page 299, it is made clear that it is not the severity of the illness that should be assessed but whether the current illness condition is an impediment to enforcement in the individual case'. 'Regarding the social difficulties [...] that a decision of expulsion or deportation enforcement for most people means a combination of dashed hopes, worries about returning to the country of residence ['home country'] and for economic and social problems. The space to take into account factors such as those must be very limited at the stage of enforcement'. 'The Swedish Migration Board does not regard that the mother's or daughters difficulties in terms of schooling and social living situation constitutes grounds for impediments to enforcement according to 12 Chapter 18§ first paragraph, the Aliens Act. There has not been any valid reason given to suspend the enforcement decision'.</p> <p>25 The Swedish Migration Board: There should be health care for the boy in the [country of residence]. The boy is not in a state of apathy (dissociative stupor) according to the Swedish Migration Board; but is showing signs of depressive devitalisation. The Swedish Migration Board's justification for rejection on impediments to enforcement: On the submitted medical certificate it is clear that the boy is showing signs of depressive devitalisation and that there is a risk that he will develop a real state of depressive devitalisation if he does not receive care. The Swedish Migration Board makes the assessment that the boy is not yet in a state of devitalisation but that he is showing signs of such a condition. According to country information, health care is available in the [country of residence]. Even if the care does not hold the same quality as in Sweden, it is judged to be adequate in accordance with the Aliens Act. From the patient note it is made clear that both parents are prepared to take responsibility for the boy's well-being. It is not made clear that the family would not have access to a social network in the home country. Regarding the boy's suicide attempt it is not clear from the patient notes how serious this ill health is or what the cause is. Any information about any medical investigation into the suicide attempts has not been submitted. For this reason, it is not possible to make any assessment with regard to the suicide risk. Overall assessment: it is taken into account that it is about a child but there is no reason to suggest impediments to enforcement. Rejection. Court of Appeal: what has been invoked is not sufficient to make it probable that they have a need for protection. 5:6 Aliens Act: the boy's poor health is not disputed i.e. that he is psychologically unwell is not disputed but medical certificates are missing. The patient notes cannot in a satisfactory way and independently be considered to document the health status of the boy. The lack of medical certificates makes the boy's health difficult to assess. Health care needs are not clear either. Nor is it shown that care is not available in the [country of residence]. No impediments to enforcement.</p>

Discussion

Children with depressive devitalisation

The current inventory was carried out during a three month period in the autumn 2011. Twenty four families were included, who had sought asylum between 2004 and 2011. They had received rejections on their initial application and most of the families had also received rejections at the final stage of appeal.

For the 60 children under 18 years of age, 30 showed symptoms of depressive devitalisation according to MAST grading 1-3, and more than half belonged to the most severely devitalised group. For other children there was information indicating they are suffering from other forms of poor mental health or that they are at risk of poor mental health.

In the discussion, the results are understood in the context of earlier observations made in Sweden since 2005. This primarily concerns knowledge from a research study including 25 asylum seeking children in inpatient care treatment [1] and the report 'The Burden They Came With' (2008), which included 33 children with severe depressive devitalisation [4]. In these reports [1, 4] 18 observations were summarised in relation to the families' situations. Ten of these observations are comparable to the questionnaire items used in the current inventory. Some comparisons can also be made with the results from a national survey including 424 children with depressive devitalisation from 2005 [11].

The children's ethnicity and nationality

The children with depressive devitalisation were born in nine different countries. As in previous reports [1, 4], most of the children are from Serbia and Kosovo as well as former Soviet republics. The majority of the children belong to minority groups (Romani and Uyghur people).

The reasons that the children with depressive devitalisation are from these particular nationality and minority groups are probably several: refugee migration is by and large a process of selection (this is the aim of a regulated and restrictive or "controlled" migration). Who is seeking asylum in Sweden depend on factors such as the geographical location of Sweden, international agreements, the ability to leave and refugee routes from the countries that people are forced to leave. After the forced migration journey there is also a selection in Sweden: the majority of people applying for protection in Sweden are rejected in the first instance. Which groups are granted residency depends in part, on individual needs but also on political decisions. The current inventory shows that children with depressive devitalisation have been exposed to a high level of violence such as physical abuse, rape or abduction, often due to their ethnicity. Violence can cause psychological problems

regardless of cultural belonging [12] since suffering due to violence is a general human emotion. Similar states to depressive devitalisation have been documented within child psychiatry, and catastrophic- and defence psychiatry, as well as under the construct 'pervasive refusal syndrome' [1]. Similar symptoms are, as seen in the introduction, also experienced by children born in Sweden. Cultural-, religious-, gender-, or other forms of group belonging can be a supportive mechanism for the individual but it can also form part of a process of exclusion [12]. It is important to be very careful about conclusions that state that the children are developing depressive devitalisation due to stereotypical perceptions about behaviours or patterns of behaviours of the group the children belong to.

Solicitor Sten de Geer suggests that the reason that the inventory shows that many Romani children from Serbia and Kosovo have developed depressive devitalisation is not random [10]. Instead of suggesting that it is the children's ethnic belonging, which makes them behave in a certain way that could explain or worsen the symptoms, the reasons are rather on a structural level. As de Geer suggests, there are reasons to question whether the children have any access to an asylum process in a real sense in Sweden. Decisions about rejections with immediate force, is often made for Romani people without the right to appeal based on substandard and stereotypical assessments and without or with deficient official representation [10].

Inadequacies in the practical application of the Aliens Act's regulation and international conventions about the right to protection, is a major problem [10]. It is likely that this, in combination with not being believed, experiences of potentially traumatising life events, harassments, persecution, the unsafe and insecure situation the children are experiencing in Sweden, a fear for the future and a lack of trust are contributing to the development of depressive devitalisation.

Age distribution

In the current report the age distribution is 6-17 years (MAST 2 and 3) for children with severe depressive devitalisation. The age distributions for the four children at risk of depressive devitalisation (MAST 1) are 1-16 years of age. The age distributions in previous reports were between 7-13 years [1], 7-15 years [11] and 7-17 years [4]. The reason why children are younger in the current inventory may relate to a greater awareness about the symptoms of depressive devitalisation, in particular, about identifying children at risk. It may also be a sign that younger children have been exposed to potentially traumatising life events. It is thus important to be alert to identifying children at risk, and to assess and offer preventative health care interventions.

Unaccompanied children

Previous reports did not include unaccompanied children [1, 4 and 11]. There are no unaccompanied children in the current inventory. However,

unaccompanied children and children without parents were included in the report presented by the Swedish Migration Board from March 2011[9].

Gender distribution

Previously, it has been reported that the gender distribution between girls and boys has been relatively equal. In the report by Bodegård (2006) [1] and in the national survey from 2005 [11] the distributions were also equal, as well as in the most recent report from 2008 where 18 of 33 children were girls [4]. The result of the inventory is slightly different in that 19 girls and 11 boys show symptoms of depressive devitalisation according to the MAST grading. In other words, the gender difference in the present report appears to be greater than what previously reported. Among the siblings there is no gender difference. The reason for this observation is not clear and should not be generalised due to the way in which the inventory was undertaken.

The first born child

Previous studies have shown that it is primarily the first born child in the family who has been suffering from depressive devitalisation [1, 4 and 11]. The present report does not support this observation. Thirteen children who are showing symptoms of depressive devitalisation are first born. However, four of the 13 first born children also have siblings with symptoms of depressive devitalisation.

Severely traumatising life events amongst the children

The most common forms of violence have been reported under the heading 'potentially traumatising life events'. These include events that can trigger posttraumatic stress syndrome (PTSD) and/or depression amongst people who previously have been healthy and well-functioning prior to the event or events [13] and thus differ from frustrating every day events or traumatic loss [13]. It is striking that for 22 out of 24 families there is documentation that children with depressive devitalisation have experienced severe violence and violations and/or have been witness to the effects of severe violence and violations of a close next of kin (parents and/or siblings).

Many of the children have been either themselves exposed to or witnessed their parents and sibling being beaten, raped and exposed to threats to life or of violence. Further circumstances that could affect the experiences and possibilities to 'cope' are that there have often been more than one perpetrator at the time of the event, and on many occasions the traumatising life events have happened at night. A number of children have been abducted; to be taken from one's parents, the very persons protecting the children, is a very severe experience for any child and their parents [2].

Exposure to violence and abuse is often under reported. In particular, when it comes to humiliating abuse of for example of sexual nature, and when children are the victims. It can thus be expected that the results of the inventory concerning 'potentially traumatising life events' is a minimum and

it is probable the figures are underestimated. Previous studies also show that children with severe depressive devitalisation have had a high level of traumatising experiences. Bodegård (2006) observed that 24 of 25 children had been exposed to severely traumatising life events, often abuse [1]. The report 'The Burden They Came With' [4] shows that all children had experienced dramatic events prior to the refugee migration journey. Potentially traumatising life events were not included in the national survey from 2005 [4 and 11].

The family situation and the parents and adult siblings health

Many parents to children with depressive devitalisation have been physically abused, have had their children abducted, have been raped, detained, imprisoned, tortured, have had close next of kin (including their children) murdered, and have been exposed to threats to life or of violence.

It is also clear from the inventory that the parents to the children are living under high psychological pressure; in most families there is information about the poor mental health of at least one parent and of a lack of capacity to care. Nearly all adult siblings are suffering from poor mental health. The high level of poor mental health and a lack of parental capacity to care are similar to Bodegård's (2006) observations [1]. Severely reduced capacity to care was prevalent in more than half of the cases in the current inventory.

Many families consist of single parents with children with severe depressive devitalisation. One mother is caring for two children in need of nasogastric tube-feeding. That the single parents are living under great pressure is clear. The reasons can vary and can impact in various ways on the family's situation. In many cases the partner of the single parent is no longer alive or has disappeared. Family separation and the reason for this can contribute to the pressures posed on the children and their parents. The parents can have been forced to leave at different points in time and for this reason have not been able to be together. Long term pressure could also be a reason for parental separation.

Bodegård (2006) suggest that the parent's interpretation of the surrounding world is more important to the child than external information provided by other sources [1]. This is a logical and reasonable interpretation, in particular considering the life events the families have been through, where trust in the surrounding environment has failed due to the experiences the children and their parents had through in terms of harassments, threats of violence and violence exposure, abductions and imprisonments and where family separation is common. From a family perspective it is important to find out what the children fear, in order to understand the fear of the child but also because the parents are affected by the wellbeing of their children [14].

It is clear that for children who have not been picked up by the health care system, there is very little information about their situation and life experiences. Considering the life situation and life events that are revealed for the

children with severe depressive devitalisation, the health situation of the siblings ought also to be assessed given the high prevalence of poor mental health and uncertainty when it comes to residency it is probable that the atmosphere is characterised by for example hopelessness, helplessness and uncertainty [1 and 4], with obvious risks also to other children's mental health within the family. The siblings to the children with depressive devitalisation, where health and life circumstances are missing, should thus be better acknowledged.

Medical description of depressive devitalisation

Gradual worsening of the illness

The inventory shows that the children are experiencing a gradual worsening of illness, and this is in line with previous reports [1, 4 and 15]. Bodegård had already highlighted in 2005 [3] the need for preventative interventions, which at an early stage could prevent and treat the effects the hopelessness and helplessness. The current inventory suggests that the need for preventative interventions is still great. The gradual worsening of the illness means that there is a possibility to engage the children at an earlier stage to prevent a deterioration in which the child becomes unable to contact. This demands that the child and parents are listened to, to understand how the child is doing and what the child and/or family have been through.

Case workers and decision makers at the migration authorities have a responsibility to ensure that the children have access to a qualified assessment of their own reasons for asylum [2]. According to the law (2008:344) on health care for asylum seekers and others and according to the National Board of Health and Welfare's ordinance that was implemented on 1 January 2012 (SOSFS 2011: (M) [16]), 6 § and 7 § (page 3), health assessments should be offered and it should include *...a dialogue about the individual's health with reference to previous and current physical and psychological health status and a part of the dialogue should concern how the health status may be affected by the individual's psychosocial situation or traumatising experiences*. For children the health assessment shall *... also include how the child is affected by the care-giver and other family members' health*.

With regards to children with severe depressive devitalisation who are lacking the ability to communicate, the assessment is made on the basis of clinical assessments in combination with narratives from parents and other persons in the child's environment [2]. This is a common way to assess patients who are not able to communicate their complaints, such as new-born babies, small children, adults who are unconscious or older people with dementia [2].

Description of illness deterioration for care, treatment and knowledge about illness development

The MAST grading has been used to identify children who are described as having depressive devitalisation in decisions and on medical certificates. The MAST grading was chosen to categorise the children's symptoms and to be able to make comparisons for example with the latest report by the Swedish Migration Board [9]. Bodegård [1] clinical assessment criteria, 11 symptoms grouped into four domains were developed with the aim to be able to classify the seriousness of the condition. The criteria appear to be able to provide a significantly more detailed clinical picture of the children's condition. These assessment criteria presuppose, however, medical skills; blood samples are also included in the assessment to examine metabolic disturbances and stress hormone pathology. Because the child's condition is extremely serious, it is an assessment that requires specialist competence, not unreasonable to ask for considering underlying causes and possibilities for rehabilitation. The MAST grading on the other hand, has the advantage that children at risk of as well as with severe depressive devitalisation can be assessed by others, including for example teachers. It is in this way the MAST grading appears to have been used in the survey by the Swedish Migration Board [9 and 17]. The disadvantage, however, is that the description of symptoms in the MAST grading is not as detailed (the SOU grading is even more reduced), which means that important observations can be missed. One example is children who wail or scream which is documented in medical certificates in the current inventory. This symptom is missing in the MAST and SOU grading, however, forms one part of Bodegård's clinical assessment criteria: domain 2, symptom 6 [1].

When it comes to diagnosis, PTSD is the most common form discussed in the legal documents. The diagnosis PTSD presupposes that the individual has been exposed to life threatening events, which may induce long-lasting psychological symptoms such as concentration difficulties, flash-backs, avoidance, nervousness and sleeping-problems. PTSD is also common in combination with anxiety and depression. A hypothesis of the illness process in the case of depressive devitalisation, which could possibly be demonstrated through clinical diagnosis is devitalisation due to *long-term posttraumatic stress syndrome and chronic stress reaction due to severely unsafe living circumstances*. This progression is also in line with the description of 'pervasive refusal syndrome (PRS)', which is a chronic traumatic stress condition in an environment of hopelessness, helplessness and uncertainty over time [1].

The identification of established diagnoses or symptom dimensions can provide a good description of the clinical picture that the children are presenting with, which can facilitate preventative interventions and the dissemination of knowledge amongst health care personnel and treatment. They

should be complemented by other needs assessments, which provide indications of reduced functioning and/or quality of life.

An advantage with different types of assessment is that, in combination with diagnosis, it is possible to relate it to international discourse. Comparisons can be made to explore and increase the understanding of depressive devitalisation amongst children and adults, who have experienced potentially traumatising life events and possible variations in cultural expression. This can contribute to improvements in validity and reliability of diagnosis and symptom dimensions and did the dialogue with non-care giving organisations.

Inadequacies in the documentation about the children's illness condition

Overall the prevalence of medical diagnoses and other types of assessments of reduction in function, MAST, SOU, C-GAS, is sparsely reported in the current inventory.

One reason for inadequacies in the assessments of depressive devitalisation, diagnosis and needs assessments can be a lack of knowledge within health care about how to assess a child with symptoms of depressive devitalisation and how best to treat and care for these children [18]. It is important to recognise that despite the methods used to describe the children's illness, an assessment and its documentation is necessary. The primary aim is to ensure competent treatment and to make available good quality care for the child.

Rehabilitation and recovery

There are children in the inventory who during the period were granted a residence permit. As far as we know their condition has not yet improved from their condition. For children with residence permits the type and content of care delivered is important. Previous studies indicate that a residence permit constitute the beginning of the creation of a safe environment, however, the level of care and its content is also of major importance [1]. The time of the illness onset also matters when it comes to the understanding of the child's illness progression. This type of information is missing in the current inventory.

Generally, relevant information about the journey the children have undertaken to Sweden is missing in the medical certificates. It is important to highlight that it is not the actual route travelled but the journey that took place and their meaning. Research shows that forced migration journeys can be very dangerous, vary in time and involve much uncertainty with regards to survival and when and where the journey may end [19]. The journey can also incorporate experiences that can contribute to coping and recovery.

The justifications made in the rejection decisions show a need to increase the knowledge amongst the migration authorities personnel about the need for a safe environment for children with depressive devitalisation and/or oth-

er types of psychological problems (such as suicide or PTSD). To minimise the risk of re-traumatisation and to give the child opportunities to regain hope for the future are prerequisites for recovery.

With more knowledge about what happened to the children, the possibilities for adequate care, prevention and possibilities to revert the illness deterioration are also improved. This demand a treatment (by health care and migration authorities) built on respect. However, this also means that no pressure or force is made on the child to talk, or that the child (and/or the child's family) is undermined since then there is a risk that the child is placed in a situation of fear or is re-traumatised, which deteriorates the child's condition.

Hence, permanent residency for children with depressive devitalisation is hence important, for survival, to reduce suffering and prevent illness deteriorating, and because children need and have a right to stability and safety.

The legal process

Proof of identity and 'pre-judgement negotiation'

The fact that few people have submitted a proof of identity, which has been judged to sufficiently prove or make the identity probable is perhaps not so difficult to understand. The use of identity documents varies between countries; in Sweden proof of identity is often required in everyday life, and this is vastly different to for example other countries within the EU. In a situation of forced migration, it may not be possible to get an identity document (for example from the home) or there may not be time prior to escape. It can be difficult, perhaps near to impossible because of the danger to life it may involve for people who are persecuted, to apply for identity documents. People may also be deprived of their identity documents when fleeing or be forced to do away with them. Even at the time of application in Sweden, it can be dangerous or difficult for the person applying for protection to send after proof of identity from the country to which he or she had to leave. The Migration authorities appear to a fairly high degree to accept documents that are sufficient to make residency likely. Considering the high number of refusals of asylum applications, it would however be interesting to explore how much weight is attached to the possibility of proving ones identity; to what extent is the type and the verification of identity contributing to the assessment and decision about the need for protection?

Regarding 'pre-judgement negotiation', the request is often not submitted. This raises the question whether 'pre-judgement negotiation' is not considered necessary to investigate misunderstandings or ambiguities? It is apparent from nine cases in where an application for 'pre-judgement negotiation' has been submitted that it has only been taken place in two. Could it be that

applications for ‘pre-judgement negotiation’ are not submitted because of a high risk of rejection? What does this mean for the possibility to make the child’s voice heard in the asylum process?

Decision-makers assessments of severe mental illness, need for care and future illness progression

There are several examples of the migration authorities decision makers making their own medical (including psychiatric) assessments of the children’s needs without the medical competence to do so.

One example is the reasoning around the increase in a child’s weight. Nutrition and energy infusion for children with depressive devitalisation through nasogastric tube feeding, require specific skills. The amounts infused must be balanced carefully so that the child will not decrease or increase in weight [2]. Measurements of metabolism in children with depressive devitalisation have shown that their metabolism is often very low, often just above the threshold for survival [2]. The fact that a child with nasogastric tube feeding has increased in weight is hence not an argument for rejection. Nor is it an indication of misdiagnosis or that the child could do well without health care input.

It is clear from the inventory that there are reasons put forward by decision makers in relation to the level of severity of the depressive devitalisation, where decision makers seem to suggest that the children are not sufficiently ill. One example is the child, who the Swedish Migration Board considers to have signs of depressive devitalisation however they argue that he is not actually in that state. The Swedish Migration Board dismisses the patient notes taken by the children and adolescent psychiatric services (the institution specialised to understand and treat children, who for example have tried to commit suicide). The Swedish Migration Board argues that the patient notes- which is the basis for health care personnel in their internal care communication, cannot sufficiently document the boy’s health. The decision makers then argue that on the basis of the patient notes, they are not able to assess the suicide risk.

In those cases where the documentation is judged not to be sufficient, decision makers ought to request further documentation from the health care services so as to ensure that the child will not be harmed by a negative decision. It is, after all, the case that the migration authorities have a duty as part of a well-functioning and secure legal system [20] not to expose children to harm and to abide to the international conventions on human rights ratified by Sweden, such as the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities [21]. It is however outside the Swedish Migration Board’s decision maker’s role and competence to make assessments about a child’s risk to life with regards to the child’s health. It is also outside the Swedish Migration Board’s medical officers to make an assessment about the risk to a child’s life without first having made

a correct medical assessment, which means that the medical officer has to meet with the child.

The current inventory indicates that the children's experiences of potentially traumatising life events are often made visible through medical certificates and not through the Swedish Migration Board's asylum investigation. It seems as if it is that after the application of asylum or protection has been rejected, further information arising from the medical certificates are not considered as new reasons for a need for refugee status or protection. The Swedish Migration Board is however obliged by law to investigate children's own reasons for asylum. One reason mentioned in the rejections is shortcomings in evidence (i.e. medical certificates) to demonstrate a need for a residence permit. It is however important that even if the submitted documentation is limited, from a legal point of view it is reasonable to assume that if it is mentioned in a certificate *or* patient notes that a child is unwell, has psychological or physical problems (as in the example with the child who had tried to commit suicide), then the child is. One reason for this may be as, previous studies, have shown that i.e. decision makers in the asylum process avoid asking children about their reasons for asylum with reference to the best interest of the child [22].

Health care access is used as an argument in rejections with reference to general country information. According to the Swedish Society of Medicine the Lisbon Declaration's rules around health care continuity means that ... *a doctor may not participate in the expulsion of an ill child without personally having made sure that the child will access a continuation of health care in the country of residence [home country]* (page 1942) [24 and 25]. To not ensure care continuity for children with depressive devitalisation can constitute a direct threat to the child's life and possibilities for recovery [2]. This, argues the Swedish Society of Medicine, is also applicable to assessments of certificates used in the assessment of impediments to enforcement (whether or not the child can cope with the expulsion): *to only certify that the child can cope with transportation is not in line with [...] the professions code of conduct* (page 1942) [23].

Children with depressive devitalisation versus the Swedish national interest

The number of person granted residence permit in Sweden due to refugee or similar reasons has reduced since 2006 [25]. At the same time there has been an increase in the number of residence permits due to work. This is in line with Ministry of Justice's inquiry published in May 2011 about *particularly distressing circumstances and impediments to enforcement* [26]. The authors of the report write that the Swedish Migration Board is making too discretionary assessments in their application of the law concerning particularly distressing circumstances (which in other words, can be interpreted as the Swedish Migration Board is too generous in its assessments concerning par-

ticularly distressing circumstances). The inquiry has a chapter describing what is included in the assessment of the individual's health status (for more information, see Attachment 4 in the present report). It says that there is scope for granting residence permits on the grounds of life threatening illness (physical or mental) but that the feasibility for health care to be provided in Sweden shall be taken into account and as should whether adequate care is available in the country to which expulsion is planned. Furthermore, it states that the health care should lead to a significant and durable improvement or be a necessity for life of the individual concerned.

The inventory shows that the arguments relating to health status in the Ministry of Justice's report about particularly distressing circumstances are reflected in the rejections. One example is where it is described that the child is spoon fed (this is something the health care providers were aware of when the health certificate was issued) however, as the child is cared for in the home and has not become better, residency is rejected. In other words, can it be that for the child this becomes a very exposed position: if the health care providers do not provide care or support, important to the child's recovery, this also contributes to a more legally uncertain process since decision makers can interpret this as if the child is showing an inability to improve in health?

It is also explicitly mentioned in the Ministry of Justice report that the costs of care for some illnesses can form a basis for a residence permit to be refused. In this way, this becomes a near to impossible situation, to say the least: the care that children with severe depressive devitalisation needs can mean significant effort for an unspecified period of time. This is important for the child's life and society in order not to violate fellow humans and become part of a destructive process in which children are mal-treated. Is there a risk that the migration authorities are making the decisions that care for the children are too costly? If so, what qualification does the decision makers have to take such a decision and go against international conventions on human rights ratified by Sweden? Previous studies have shown that children's rights are considered secondary in relation to Sweden's interest to reduce migration [22]. Given that there has been an increase in the number of residence permits for reasons other than refugee reasons or similar, as presented by the Swedish Migration Board, maybe it rather refers to control migration in terms of productivity and the individual's ability to contribute to the economy?

In the Ministry of Justice report it states that it is the durability of the health status that shall form the basis for residence permit, and that the longer the durability of health the stronger the support for the granting of a permanent residency (Attachment 4). Does this mean that people who have a good development of health primarily should be given residency? Is it so that if the events in the country the child and the child's family is coming from is not judged to form a basis of a decision of residency due to refugee

reasons or reasons of protection, then it is ok to presume that the child can receive health care in that country [that the child and family have fled] without any risks? In this way, even a child with severe depressive devitalisation can be expelled? In other words, if refugee or reasons for protection are not granted, then particularly distressing circumstances are not applicable either (due to reasons of costs)?

But if a child with severe depressive devitalisation is sent back to the country the family argues they have fled, what happens then? What risks are the child exposed to if he or she is not able to access health care in practice? Or if the child due to fear is not able to access the prerequisites for successful treatment i.e. to feel safe, trust and hope for the future? What happens with the child, if the child and his or her family are forced to move again?

In the negative decisions it is evident in what desperate state children with severe depressive devitalisation are in. It is important to remember that there are possibilities to help the children to recover from devitalisation and there is also a responsibility to do so.

Other avenues, other choices

In the work with the most recent Alien Acts, there is a will to ensure that the Convention on the Rights of the Child and the first paragraph of a law shall be given a substantial impact in praxis [2]. In the Committee on Social Insurance's [Socialförsäkringsutskottets] work on the current Aliens Act 2004/05: SfU17) it is also argued that the application is not meant to become tighter.

The current inventory shows that there is no mentioning of the indicative decisions or preliminary work the Aliens Act in the court decisions. This could however be done, and in this way the legal interpretation could become more generous. Health care services can become better at early recognition of and offer of treatment to children who are at risk for depressive devitalisation. Systems can develop to better ensure that medical doctors and other care providers follow the ethical code of conducts that form the basis for their registration. There is scope for courts and authorities to ensure a legally secure and more humane assessment and judgement. Politicians can express support and enable a process which is in line with international conventions on human rights.

Limitations

There are a number of limitations important to highlight, which affect the quality and generalisability of the inventory results. The sample derive from informal networks, which means that there may be a selection of children from certain parts of Sweden, and not all families with children with depressive devitalisation may have been approached. The information derives from

what is accessible through court decisions and certificates. In several cases, decisions and certificates have not been accessible. First-hand information from the children is by and large totally missing in most cases. In the included families, where children do not have any medical certificates, there is most often no information about them at all. The information has been documented by various people; decision makers, care providers, teachers and so on.

The questionnaire used in the inventory was put together over a period of about a month, and has due to time pressures not been tested prior to use. The questionnaire was filled out by various persons, with different experiences and this may have meant some variation in terms of how the questions have been answered. The case descriptions have been chosen to highlight trends or aspects that have been identified as particularly important. The material is extensive and the inventory was carried out under time pressure, which may mean that some information can have been missed. Decisions, court decisions, certificates (medical certificates and other types of certificates) are missing in some of the families files. When it comes to the certificates, these have in some cases been mentioned in the decisions but have not been found in the files. One example is a family where a child is nasogastric tube fed but where information about the child is missing in the negative decision and other information attached to the file. In cases such as this, the working group have made attempts to access the information; however, this has not always been possible (primarily due to a lack of time). Relevant information may have been missed which in turn may have affected the frequencies presented in the report.

To decrease inaccuracies and increase the quality (including trustworthiness, validity and reliability in the selection of text), the working group have had regular meetings and discussions around method (for example how the questionnaire items have been interpreted, what type of answer the questions provides, and the relevance of the questions in relation to accessible documentation), interpretation and presentation of results. The frequencies have been recorded in Excel and have after recording been checked against the information in the files. The inventory was initiated by the Swedish Paediatric Society's Working group for Refugee children, and they have also taken part in critically appraising the report with written comments; the report was revised in response to some of these comments.

How does the inventory differ from a research study?

The inventory is not a scientific research study in the sense that a research study involves a detailed project plan, research question, theory and so on, which requires more time. The inventory is based on existing information with the aim to draw attention to the children's acute needs. It has not been submitted for ethics approval. As far as possible, research principles and ethical guidelines have been followed. This procedure in combination with the

fact that the inventory involves existing data constitutes an insignificant risk of injury or discomfort to the individuals concerned [27]. The risk that human dignity is violated is deemed to be greater if the inventory had not been carried out.

Missing observations

Previous reports [1 and 4] contain observations about the personality of the children who are ill and the time of the onset of illness (before or after rejection on the asylum application). This type of information does not exist in the available decisions and certificates. Information about parents' socio-economic situation is also missing. Information about the children's previous health status was not included as a specific question in the questionnaire, and knowledge about potential differences in the illness progression between children with depressive devitalisation and other children within the same family who do not present symptoms is therefore limited. Information about previous health status is, despite the lack of a specific question, mentioned in half of the cases.

Previous reports contain information about recovery after residency [1 and 4]. This information is for obvious reasons missing in the current inventory. Four children with severe depressive devitalisation received residence permits soon after data collection ended. One family with a child with severe depressive devitalisation have received interim reprieve [in Swedish: inhibition]. So far, there has been no information suggesting that any of the children have started to recover. Previous experiences show that it often takes several months before safety within the family is established and thus recovery starts. A systematic follow-up has not yet been made. It would be relevant to follow-up children with various degrees of depressive devitalisation, and listen to and analyse their experiences. Finally, for an increased understanding about the processes of decision, making it would have been useful to also include children who presented with depressive devitalisation during the same period but who received permission to stay and to explore what may differ between these groups.

Conclusion

The child's voice is missing

It is concerning that the experiences for many children are not at all visible in the asylum process. With regard to cases where information about the children's experiences is available, it seems that it has often emerged later than at the first instance, i.e. during the process of appeal or health care contacts. Since the families are not considered to be in need of refugee status or protection, this enables an assessment where access to health care in the

country the family is to be expelled to can be deemed possible (on the basis of country information). This in turn contributes to a rejection on *particularly distressing circumstances* [as regardless of illness severity, health care can be accessed elsewhere]. At the stage of enforcement, the only thing tried is whether deportation is possible. A lack of information about the children's own reasons for asylum early in the legal process, could be due to factors such as how information has been sought, what type of questions have been asked, who was asked, about what and how, as well as judgements on what constitutes trustworthy information. A child who is unresponsive will not be able to answer questions so information must be sought from other sources e.g. parents. It may also be that both the children and their families find it hard to talk about their experiences.

A need for preventative intervention to prevent a deterioration of the illness

Considering the difficulties in communication [with children with severe depressive devitalisation], the migration authorities must posit a will and competence to understand both verbal and non-verbal signals, at all levels of the judicial process. Furthermore, preventative care is needed so that these children can access the care and help needed for them to be children in contact with their environment, instead of being forced into a state of dissociative stupor as now. This indicates that it is important to pay attention to children at an early stage in the asylum process, to listen to what parents feel about their children's well-being and that children have access to qualified assessments of their health and illness.

A need for knowledge development

Remarkably, narratives that emerge from the decisions and certificates often contain information about serious violence that the children (and their families) have endured. In the decisions, however, the situation is often portrayed as if the narratives and the children's depressive devitalisation are linked to parents' dashed hopes and worry over economic and social problems instead of the illness expressed in medical certificates and/or a need for asylum and protection. This suggests that there is a need for more and better knowledge transfer to the migration authorities' decision makers about what effect life events such as serious violence, rape, abduction, threats of violence can have on poor mental health, and also what are common reactions and what can help or worsen health and the possibility of a normal life for children with these experiences. To find out more about children's experiences an approach based on respect is required, and that pressure is not put on the child to force the child recount their experiences. Then there is instead a risk that the child is placed in a fearful situation, which increases the likelihood of poor mental health and deterioration in health.

Better documentation and trust in caregivers statements

Decisions and health care certificates are often inadequate when it comes to the children's situation. Health care provision needs to be documented so as to assure proper care and communication. It is however important that, even if the information given by health care staff is limited, from a legal perspective the basis must still be that if it is documented in a certificate (or journal extract) that a child is not well, then the child is not well (for example if it states in the journal extract that a child is suicidal then the assumption must be that the child is suicidal) In cases where the documentation is not sufficient, decision makers need to request further information, with the aim to ensure that children are not exposed to risks. This is also important in order to uphold a legally secure system.

Well-founded fear and particularly distressing circumstances

There is a need to reflect on what well-founded fear means and how fear may be expressed, and what 'particularly distressing circumstances' really means in relation to the children. Fear of further violence and abuse on return/repatriation is a very serious risk factor in chronic severe psychological stress. It is also a risk factor in severe depressive devitalisation. Factors such as abduction, rape or witness to rape or serious beatings, are child specific reasons for asylum. If there are indications that a child has these or similar experiences, it must be assessed by personnel who are qualified to do so, to assure a legally secure and humane procedure.

The children in focus

When the economy is constrained it is urgent that serious efforts are made in order not to lose focus on what is important. The current inventory shows that children in states of very severe depressive devitalisation have experienced serious violence, have received a substandard treatment in Sweden and lived under great uncertainty about the future under a long period of time. This is in a context where parents and siblings also have been exposed to serious violence and are suffering from poor mental health. The inventory shows also that authorities in Sweden are aware of how ill these children are but for various reasons do not take the responsibility they should when in contact with children who have been exposed to serious violence. Sweden is a country with a well-functioning health care system. There is knowledge about how children with severe depressive devitalisation can recover and about what may cause severe depressive devitalisation. The children and their families need immediate peace, care and hope and thereby the possibility for recovery and a dignified life. Sweden can afford this and has a responsibility in accordance with international agreements on children's right to a life of dignity.

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Attachment 1 Sources of information for MAST grading

Table. Knowledge gathering about depressive devitalisation for children under the age of 18 and MAST grading

Type of information source Combination of information derived from the documentation ¹ :	The number of children with depressive devitalisation per MAST grading		
	MAST 1	MAST 2	MAST 3
1) The words "nasogastric tube feeding" or the child "has an ng-tube" ¹ 2) Clinical diagnosis 3) MAST/SOU grading	0	1	5
1) Clinical diagnosis 2) MAST/SOU grading	0	0	1
1) The words "nasogastric tube feeding" or the child "has an ng-tube" ¹ 2) MAST/SOU grading	0	0	4
1) The words "nasogastric tube feeding" or the child "has an ng-tube" ¹ 2) Qualitative narrative (symptom and/or description of behaviour) in questionnaire, medical certificate and court (narratives) ²	0	0	4
1) Clinical diagnosis 2) Qualitative narrative (symptom and/or description of behaviour) in questionnaire, medical certificate and court (narratives) ²	0	2	1
1) Qualitative narrative (symptom and/or description of behaviour) in questionnaire, medical certificate and court (narratives) ² 2) MAST/SOU grading	1	0	0
1) Qualitative narrative (symptom and/or description of behaviour) in questionnaire, medical certificate and court (narratives) ²	3	5	4
TOTAL (n=30)	4	7	19 ³
Other type of poor mental health or at risk of poor mental health		10	
Information/documentation is completely missing; no information available regarding health		20 ⁴	
TOTAL		60	

¹The information about nasogastric tube or ng-tube feeding mainly derives from medical certificates (but also through the questionnaires and court decisions). ²Overall, the qualitative description, which mainly consists of symptoms and/or descriptions of behaviour is weak. ³For 14 of 19 children, it is mentioned that the child receives feeding through ng-tube. ⁴The information is missing for 10 girls and 10 boys, Note: the MAST-grading was applied on available information by the first author of the report Karin Johansson Blight.

Attachment 2 MAST grading of depressive devitalisation

The grading of depressive devitalisation can be described as follows:

Grade 1. Depressive state

Asylum seeking children, who exhibit clear signs of depression, constitute a group at risk of entering into a devitalised state. These children are passive, show little interest in other people, and mobility is slow or characterised by unrest. Appetite is poor, but the child can eat and drink sufficient amounts. The child is also caring to some extent about their daily routines, however, does so with no interest or engagement.

Grade 2. On the way to devitalisation/apathy/lethargy

A child who is deteriorating into a devitalised state makes limited contact, only nods in response or replies with a few words, and just about reacts to single events. Mobility is reduced, and the child must be asked to move, or to get help or support to move within or outside the home. Appetite is limited; parents have to encourage the child to eat since the child itself displays little interest in food or cannot feel hunger. The daily routine is maintained with the help of parents or through encouragement by them.

Grade 3. State of devitalisation/apathy/lethargy

The state means that the child is unable to contact, eyes are shut or the child looks to the floor and displays none or very limited interest in the outside world. While mobility is very limited, the child is predominantly bed-ridden and must be helped to move. Food intake is through nasogastric tube feeding or the parents must feed the child. Furthermore, the child is experiencing difficulties or finds it near to impossible to continue with daily routines such as maintaining hygiene and getting dressed; the child may be incontinent and is often unaware of such signals, and cannot get dressed independently.

The assessments of functional level and the division of children with depressive devitalisation into 3 groups is not a diagnostic instrument. It is a fundamental prerequisite to make visible these children's psychiatric and medical care. In other words; it is used to define a target group. The child psychiatric diagnosis can still be for example, depression, PTSD or PRS (Pervasive Refusal Syndrome). Another extremely important function for assessment of functional level has been that it has enabled a common language between the different clinical disciplines.

From reference: Sörensen, P. (2011) Survey of children with depressive devitalisation. [Kartläggning av barn med uppgivenhetssymtom]. The Swedish Migration Board. Migrationsverket Mars 2011. Page 2.

Attachment 3 Prevalent diagnosis

F32.1: Moderate depressive episode

- **F32.2:** Severe depressive episode without psychotic symptoms
- **F32.3:** Severe depressive episode with psychotic symptoms
- **F32.8:** Other depressive episodes
- **F32.9:** Depressive episode, unspecified

F43.0: Acute stress reaction

- **F43.1:** Post-traumatic stress disorder
- **F43.2:** Adjustment disorders
- **F43.8A:** Other reactions to severe stress, unspecified
- **F43.8W:** Other reactions to severe stress, other than burn-out
- **F43.9:** Reaction to severe stress, unspecified

- **F45.3:** Somatoform autonomic dysfunction

F94.0: Elective mutism

- **Z61.7:** Personal frightening experience in childhood
- **Z63.4:** Disappearance and death of family member
- **Z73.8:** Other problems related to life-management difficulty
- **Z91.4:** Personal history of psychological trauma, not elsewhere classified
- **Z94.0:** Kidney transplant status

From:

World Health Organization: The ICD-10 Classification of Mental and Behavioural Disorders Clinical Descriptions and Diagnostic Guidelines

Sök i ICD-10 och Åtgärds-koder. Swedish version accessed 28/11/2011

<http://www.internetmedicin.se/icd/icd.asp?avssCode=F00&avseCode=F99&klass=KSH&lastScroll=0>

ICD-10Version:2010. English version accessed 29/02/2012:

<http://apps.who.int/classifications/icd10/browse/2010/en#/Z62>

Attachment 4. Health status in the Ministry of Justice's investigation

The preliminary work indicates that a residence permit may be granted with legal support if the foreigner has a life threatening physical or mental illness or is suffering from particularly serious functional disability. In such a context, whether it is reasonable to provide health care in Sweden shall also be considered.

In the assessment of the individual case, the health care should be expected to lead to good results through a significant and sustainable improvement in the foreigner's health status, alternatively be vital to life. In the assessment of whether this is reasonable, it must also be considered whether adequate health care can be provided in the country of residence ['home country'] or in another country to which the foreigner can be sent. Even if Sweden in some cases can offer a significantly better health care than that which can be provided in the person's country of residence ['home country'], this cannot on its own justify residency in Sweden.

Moreover, the Government argues, that the total economic costs of health care for certain illnesses can be such that a residence permit should be refused. In the individual case, this balanced consideration that should be achieved between the health condition, the foreigner's situation in Sweden and the situation in the country of residence ['home country'] leads to the requirements of how ill or healthy a foreigner must be for it to be reasonable to send him or her to a specific country, not being the same.

Another reason mentioned in the preliminary work, which could constitute reasons for the granting of residence permit, is if the enforcement is such that the expulsion or deportation would result in a serious risk to the foreigner's life or health, i.e. if the health condition is such that the journey itself could pose a risk. If the illness or health care need is of a transient nature then it can, according to the Government, be relevant to grant a temporary residence permit.

The Government argues that it is the durability and development of the health status that must be the basis for the assessment of the length of a potential residence permit. The longer durability, the stronger this suggests that a permanent residence permit should be granted (Bill 2004/05:170 page 189–191).

From: Lönqvist, E., Borén, H. Particularly distressing circumstances and impediments to enforcement- a survey of the applied law [Synnerligen ömmande omständigheter och verkställighetshinder–en kartläggning av tillämpningen]. Ds 2011:14. Regeringskansliet. Justitiedepartementet. Ministry of Justice. April 2011. Pages 29-30.